Multidrug-resistant tuberculosis: integral healthcare from the discourse analysis perspective

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Objective: To analyze the experiences of multidrug-resistant tuberculosis patients from the perspective of integrality of care.

Methods: Analytical and qualitative study conducted with patients under treatment. Semi-structured interviews were transcribed and then interpreted using the French Discourse Analysis framework.

Results: Professionals were sometimes sensitive to patient needs expressed in a search for integrality, though integrality was neglected at other times. Some weakness were observed in the care network organization, such as: a lack of bonds and disregard toward the patients; lack of coordination and cooperation between healthcare levels; patients becoming the only ones responsible for their treatment; and different contexts of primary healthcare that interfered in the follow-up of patients.

Conclusion: There is a need to rethink care provided to multidrug-resistant tuberculosis patients so as to provide integral care, taking into account individual peculiarities related to both the patients’ life contexts and the process of becoming ill, and also in regard to the organization and coordination of care.

Keywords: Tuberculosis, Multidrug-Resistant; Sick Role; Comprehensive Health Care; Systems Integration.

objective: Analisar as vivências dos doentes de tuberculosis multirresistente sob a perspectiva da integralidade.

métodos: Estudo analítico, qualitativo, realizado com doentes em tratamento. Foram realizadas entrevistas semiestruturadas, transcritas na íntegra, interpretadas sob o referencial da Análise do Discurso de matriz francesa.

resultados: Notaram-se movimentos de sensibilização dos profissionais na busca da integralidade, atendendo às necessidades emocionais dos doentes, porém distanciavam-se desta em outros momentos. Quanto à organização da rede de atenção, perceberam-se fragilidades: falta de vinculação e acolhimento do doente nos serviços de saúde; falta de articulação entre os níveis de assistência; responsabilização do doente para com o tratamento e diferentes contextos da organização da Atenção Básica interferindo no acompanhamento do tratamento.

conclusão: Há necessidade de repensar a assistência ao doente de tuberculose multirresistente, de modo a assisti-lo de maneira integral, tanto em suas peculiaridades individuais relacionadas ao seu contexto de vida e processo de adoecimento, quanto ao que tange à organização e coordenação da atenção.

palavras-chave: Tuberculose Resistente a Múltiplos Medicamentos; Papel do Doente; Assistência Integral à Saúde; Integração de Sistemas.

Objetivo: Analizar el tratamiento de los enfermos de Tuberculosis Multirresistente bajo la perspectiva de la integralidad.

Métodos: Estudio analítico, cualitativo, realizado con enfermos en tratamiento. Fueran realizadas entrevistas semiestructuradas, transcritas integralmente, interpretadas bajo el Análisis del Discurso de matriz francesa.

Resultados: Se observa movimientos de sensibilización de los profesionales en búsqueda de la integralidad, atendiendo necesidades emocionales de los enfermos, pero distanciados en otros momentos. Frente la organización, se reconoció: falta de vinculación y acogida del enfermo; falta de articulación entre los niveles de asistencia; responsabilización del enfermo frente al tratamiento; y diferentes contextos de organización de la Atención Básica interfiriendo en el tratamiento.

Conclusión: Hay una necesidad de repensar el cuidado del paciente con tuberculosis multirresistente, con el fin de asistirlo completamente, tanto en sus peculiaridades individuales relacionadas con el contexto de la vida y el proceso de enfermedad, cuanto en la organización y coordinación de la atención.

Palabras-clave: Tuberculosis Resistente a Múltiples Medicamentos; Rol del Enfermo; Atención Integral a Salud; Integración de Sistemas.

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INTRODUCTION

The World Health Organization (WHO) reports an important advancement in recent decades in the reduction of mortality, incidence, and prevalence of tuberculosis (TB) in the countries responsible for over 80% of the disease burden in the world. Nonetheless, the disease is still a concern in global terms because it is estimated that there is an incidence of 8.7 new cases and 1.4 million deaths caused by TB.1

One of the challenges involving TB is related to the development among patients of resistance to first-line drugs. Multidrug-resistance TB (MDR-TB) - defined as resistance to the two main drugs used to treat the disease (rifampin and isoniazid)2 - is considered a threat to the advancements achieved in worldwide TB control. Hence, it is seen as an important public health problem since it hinders prevention and treatment of the disease and also contributes to increased mortality1,3.

Globally, it is estimated that 3.7% of new cases and 20% of those previously treated will be characterized as MDR-TB. It was estimated there will be 630,000 cases of MDR-TB in 2011 among the total 12 million cases of TB.1 Additionally, the WHO estimates that there were approximately 0.5 million new cases in 2011 and that 60% of these cases took place in Brazil, China, India, Russia and South Africa.1

MDR-TB classification according to the type of bacterial resistance is used in Brazil. Hence, the disease is considered either primary - when the individual is contaminated by multidrug-resistant strains, or acquired or post-primary, a situation in which the individual has been treated for TB for at least 30 days.2

MDR-TB can result from improper use of antibiotics and is related to diverse factors such as: administration of inappropriate treatment (inappropriate prescriptions, misuse of or irregular composition of medications); lack of treatment adherence; poor intestinal absorption; failure to identify primary resistance (given inappropriate assessment of history of contacts and failure to follow-up sensitive cases); lack of or failure in providing and distributing standardized medications.1

Treatment abandonment is considered one of the main factors in the development of resistance to first-line anti-TB drugs. In this sense, operational problems of healthcare services, especially those related to the organization of the health staff, with an emphasis on the professionals’ work involving patients, are indicated as one of the main components hindering treatment success. The importance of the staff providing integral care to these patients is also highlighted.

Therefore, there is a need to provide integral care addressing individual and social aspects, taking into account the healthcare service in order to strengthen the bonds established among patients, professionals and services. These efforts imply ensuring that care provided is coherent with the reality of TB patients and with integrality as one of the principles recommended by the Unified Health System (SUS).5 Hence, it is extremely important that strategies include the close-monitoring of patients during the treatment phase5.

A characteristic that hinders the treatment of MDR-TB individuals is the follow-up of these patients in more than one health service. The Ministry of Health (MH), in agreement with the WHO, recommends that patients be monitored by a tertiary health facility in addition to being part of Directly Observed Treatment (DOT). The tertiary service, however, cannot directly supervise the treatment, given the scope of its competencies, geographical distance from the patients’ homes, difficulties designating professionals to visit patients daily, or difficulty on the part of the patients to commute to the hospital on a daily basis. For this reason, the Primary HealthCare System (PHC) is responsible for monitoring treatment.

The theoretical framework of integral care adopted in this study for care provided to MDR-TB patients was the definition provided by Starfield.6 It defines integral care as the delivery, by the health staff, of a set of services that meet the needs of the population included in promotion, prevention, healing, care and rehabilitation, together with the responsibility to supply services in other healthcare facilities as an integrating element of biological, psychological and social aspects coordinated by PHC.

Mendes argues that the creation of networks and cooperation within these networks is required to achieve integrality. Hence, the organization of services is guided by non-hierarchical relationships directed to common objectives shared by diverse stakeholders. This understanding enables the formation of a horizontal health care network composed of different technological densities and support systems without an order or degree of importance designated among them.

Coordination is understood as the existence of links between care delivered to patients, regardless of the facility in which it takes place. Additionally, it consists of the availability of information concerning health problems and pathways in different healthcare services. Therefore, coordination is influenced by the integration of various healthcare levels and by the relationships existing among healthcare providers.7 Hence, the concepts of integrality and coordination are complementary to an analysis of the complex MDR-TB condition.

PHC ensures healthcare at other levels of complexity as necessary to conform PHC as a strategy of organizing systems of health care that guide resources to the needs of the population, more specifically in the care provided to MDR-TB patients.5,9

Therefore, integral care is a priority axis in the investigation and assessment of services and healthcare systems. At the same time, we acknowledge that no organization or facility possesses all the resources and competencies required to solve the health problems of a given population in all the life cycle stages.8

The literature review showed that most studies of MDR-TB address the gene sequences of Mycobacterium tuberculosis, the medications’ adverse effects, and genetic mutations, among other topics. Hence, this review’s aim was to identify studies addressing MDR-TB from the patient’s perspective taking into account the integrality of the health system. Databases
METHOD

This analytical, cross-sectional, qualitative study was conducted in the interior of São Paulo, Brazil, in one of the seven Drug-Resistant TB Outpatient Treatment Centers, hereby referred to as “Garden Hospital”. This facility has provided care to multidrug-resistant patients since 2000 and has provided care to 44 patients in its 11 years of service.

This study sample was composed of adult patients (older than 18 years of age) who initiated treatment up to January 2011, were not in the prison system, and did not present diagnosed cognitive problems. A total of 12 patients were selected, but four were excluded because they either lived in distant cities and contact during outpatient consultations was difficult or because they refused to participate in the study. Hence, eight MDR-TB patients remained.

Data collection took place between March and May 2012. Four patients were addressed in the health service and the other four were visited in their homes, according to the availability of the patients and researchers. Semi-structured interviews were conducted based on an interview script composed of guiding questions addressing the life histories of patients; the history of the disease in the patient’s life and in the family’s life and comorbidities; potential for or histories of treatment abandonment or irregular treatment; and their experiences of attending different health services. Note that we opted for semi-structured interviews because it is a technique that allows flexibility in conducting the themes and other aspects relevant to the main focus of the study.

Interviews were recorded on a digital recorder and transcribed afterwards. This information composed the empirical material and was organized using Atlas. Ti 7. The theoretical/methodological framework of Discourse Analysis, originally in French, was used to analyze and interpret data in order to understand and produce the meanings of the MDR-TB patients’ reports.

Therefore, we sought to grasp from the patients' reports the conditions in which MDR-TB treatment is provided and the factors that contribute to its maintenance in the individual and society. We used the conception conditions of production to replace the notion of “circumstances” because we believe that the first more strongly refers to the context in which the patient is included. Conditions of production refer both to strict and immediate meanings, as well to broad meanings that consider the social, historical, and ideological scenarios that characterize the discourses.

This study was submitted to and approved by the Institutional Review Board at the University of São Paulo, College of Nursing (CEP EERP-USP), protocol Nº 1487/2011, in agreement with the ethical and legal aspects recommended by Resolution Nº 196/96, National Council of Health.

RESULTS AND DISCUSSION

The interviews were conducted with six male and two female individuals. Ages ranged from 28 to 67 years old, with an average age of 47.4 years. All the participants lived in cities of the region, with an average distance of 100 km from the facility (Jardim Hospital). In regard to the modality of treatment, five patients received DOT and were supervised during weekdays, self-administering the medication on weekends; two patients were under the Self-Administered Treatment modality; and one patient received full DOT (supervised both weekdays and weekends). In order to ensure confidentiality of the participants’ identities, one letter (D) and one number, ranging from 1 to 8, were used to identify the participants. Three broad themes emerged from the reports: “The process of becoming ill and the experience of hospitalization”; “Coordination of healthcare provided to MDR-TB patients”; and “Strategies to enable adherence to the MDR-TB treatment”.

The reports of MDR-TB patients, the focus of which were aspects related to integral healthcare, were discursively analyzed based on the literature addressing the topic. Excerpts of these reports are presented below.

All the patients had acquired MDR-TB, while two of them were undergoing their first TB treatment (D5 and D8). The other patients had already undergone at least one course of treatment, including one in which a patient (D7) had abandoned the treatment, but most had been cured. Even though none of the patients were co-infected with Human Immunodeficiency Virus (HIV), six presented other comorbidities, such as (D2) Diabetes Mellitus; (D3) atypical mycobacteriosis, smoking, and alcohol; (D5) depression, stricture of esophagus, still under investigation;
iron deficiency anemia, and malnutrition; (D8) asthma, alcohol, and smoking; (D4 and D7) smoking and alcohol. In this sense, the process of becoming ill with MRD-TB is coupled with other health problems, which aggravates suffering, in addition to often increasing the number of medications taken.

In addition to the physical/pathological aspects that permeate the process of becoming ill with MDR-TB, there is the factor that a cure requires long-term treatment and is often intermediated by the need of hospitalization. Among the eight interviewees, seven had already been hospitalized. Even though there are few studies addressing hospitalization for MDR-TB patients, MDR-TB is reported by one study conducted in a university hospital as the main cause of hospitalization among TB patients (12.5% of inpatients), with an average time of hospitalization of 29.3 days. The report of D5 can be connected to her experience with hospitalization:

I stayed for one month and they didn't want to discharge me (...), 'cause I had to be discharged with a (nasogastric) tube. They put the tube to pass on the medication because I couldn't swallow (...). I couldn't eat their food because it was awful and I had a hard time sleeping (...) I asked them to discharge me (...) 'cause I knew that if I stayed there I'd die of depression or starvation. I only know that the world outside is no longer white because you guys [professionals] sometimes enter here wearing a blue mask. The only (bad) thing was the hospital (...) the isolation (...), I became depressed, was away from my family, away from my friends, and away from my dog and my home. (D5).

This report expresses a situation of anguish, dissatisfaction and distress in the face of the need to remain in a hospital facility. The patient characterizes the hospital as a place that generates isolation, distance from the family environment, and also a place where she could not be in control of the situation, i.e., she could not control the food. The excerpt “the world outside is no longer white because you guys sometimes enter here wearing a blue mask” symbolizes the environment and her actual health condition, pale and sad. The contrast to blue, however, is ambivalent because it may be related to the hope she held in regard to the outside and also symbolizes her isolation: the mask used by the workers responsible for providing care. Hospitalization is a situation in which the individual is away from family life and has to live in a foreign environment, with other standards, people and routines. The hospitalization process may lead to negative feelings, such as disability, dependence, and loss of control for patients over their own lives and relevant places.

This individual emphasizes the exacerbation of her symptoms, linguistically materialized by the reference to “starvation” and “depression”. Consequently, it symbolizes a feeling of proximity to “death”. Given this unsettling experience, D5 tries to recover her active role in the process of life and death, requiring that she be returned to family life, and thus she tries to negotiate her hospital discharge. In turn, the medical staff responsible for providing care is sensitized and adopts a posture that approximates an integral view of the patient, because as the staff allows the patient to return home, it acknowledges the subject’s psychological and social aspects, even in the face of a complex clinical situation in which there is a need to find an alternative route for food and medication intake.

Another subject says:

I'm better now but I was skinny like a toothpick, crying, all curled up in a blanket, in depression and he (husband) buying things, supporting me like a husband would, taking care of things, going after the social worker and asking her for financial aid; because I can't work, I can't do the laundry nor clean the house, he helps me around the house. (D6).

When D6 talks, her discourse is similar to that of D5, as they share feelings of distress, linguistically marked by a recurrent allusion to “depression”. This subject, however, brings production distinctions very different from those of the previous excerpt. Though this subject refers to her domestic environment, her affective and material relationships with the support of her family members. The emotional difficulty now seems to be linked to physical weakness in the face of the process of becoming ill due to MRD-TB, which generates weakness and an indisposition or inability to perform home chores, in addition to the consequent change in the family routine.

The family may represent the main source of support for the patient, providing care. In the specific case of TB, when there is family support, it enables the patient to cope with the disease and is essential to treatment success as it enables the individual to share his/her difficulties. Another component, financial hardship, is added to the challenges faced by these subjects. This is an extremely important issue because the different forms of TB affect individuals at an age they can be economically active and therefore, be in the job market. Even though they may have jobs, the bonds are often fragile because there are no formal contracts. When these individuals become ill, they do not have rights such as paid sick leave, which affects their finances and leads to social and psychological distress. There is, within the care system intended for TB patients, the distribution of aid such as food and milk stamps and transportation vouchers, which when well-managed and distributed, are resources that can aid treatment adherence and alleviate financial problems triggered by the illness.

Another subject reports:

They [PHC professionals] ask me when I leave [the hospital] (...) about the results, and I have to inform them there (...) for instance, for now, everything is negative, the...
exams, nothing is positive. Everything is negative. Then they told me today, so I'll report there. (D8).

The MRD-TB patients attend two different facilities: PHC units and at the tertiary healthcare level. These healthcare services have a very different role in the implementation of treatment. While the referral facility prescribes medication, asks for exams, and manages adverse reactions, the role of PHC is to monitor the treatment within the patient's daily routine according to his/her context. In this sense, D8's experience in these two services pervades his discourse describing his routine, and explaining his cooperative role in the care he receives. Coordination of these services requires mechanisms to transfer information. Conventional methods include medical records and computer information systems; however, when medical records are not shared among services, the patient may need to assume the responsibility to moderate information. Nevertheless, it is important to keep in mind that these facts pass through the individuals' judgment of values, which may compromise the reliability of accounts of events.

There is another important aspect when considering the reports: the position each service assumes in the flow of information concerning the treatment of D8. When this subjects says "I'll inform", there is recognition that the PHC unit receives news produced at the tertiary level. Such a perception is materialized through the use of a control form that is generated by the professionals at the referral service at the time of the medical consultation and the form contains the prescriptions for medications to be administered distributed for the days of each month. This instrument is provided to the patient by the professionals at the tertiary level and the patient delivers it to the professional at the PHC unit to be filled at the time they supervise the administration of medication. When we consider the coordination of healthcare, which is necessary for the delivery of integral care to these patients, when standards and rules are merely reported, cooperation and negotiation between the services involved are compromised, resulting in weakness and hindering proper control of the disease.

Because these are patients come from different cities, PHC units assume different forms of organization:

I had to take the medication in the hospital [IV medication] because there was no professional available to give me the medication there [referral service], I don't know where they were (...). I said "I came to take the medication; I have to take this shot, that's all", "did you bring the prescription?" "no", "but if you don't have the prescription, I can't administer the medication", (...) "you have to have the prescription" and this and that, so I said, "but people, if I leave without this shot I won't have medication today (...) I have been coming here to take this medication for more than one year." (...) The other nurses had to wait for him (the nurse in charge), but if he goes somewhere and can't come back and like... In addition to the fact that I may forget to take the medication. I went there today (D1).

When D1 reports the event that took place in the healthcare unit where he receives DOT, D1 complains he was not recognized, that there was a lack of bonding with the service, and expresses his dissatisfaction with the way he was treated by the city's healthcare facility, materialized in his effort to be remembered by the professionals "I have been coming here to take this medication for more than one year". It is worth noting that this was the only TB patient receiving treatment in the city of origin between 2011 and 2012. Hence, we question the integrity of the organization of the city's healthcare network, since it was not efficient in negotiating for and linking this subject to the service, not structuring a mechanism to meet his peculiar needs. We note therefore, that the coordination within the city's health system is poor since there is no continuity of care provided to the patient. In a study addressing the coordination of care provided to sensitive TB patients in Ribeirão Preto, SP, Brazil, problems are reported in the flow of information among the services, characterized by discontinuity of care, with difficulty on the part of the services ensuring information is recorded. It is known that a well-coordinated system integrates information originating at the different levels of care focused on the integral care of both sensitive TB and MDR-TB patients. When information is not complemented, integrity of care is not possible; rather, it is fragile and limited, since one of those involved in not aware of the previous history of the patient accessing the service, which does not have an arsenal of information to rethink care delivery.

Still in regard to the organization of the healthcare services providing care to MDR-TB patients:

No, they don't come on the weekends. It's my brother [who also has undergone treatment] who informs them and prepares everything. (D7).

They come on Saturdays and Sundays. They only thing they don't do is to administer the serum. I tell them they don't need to, but it's the rule, right. It'd help them (...) But perhaps, if I try to help and someone ends up knowing about it, that they didn't come on the Saturday and Sunday, that I took the medication by myself, it may even hurt their reputation. (D5).

The previous reports belong to different subjects: D7 is male, has not completed middle school, is a farmer worker and was unemployed at the time of the interview. D5 is female, has completed high school, and is a retired nursing professional. The treatment modality employed for these two individuals is different. Both receive DOT at home, but D7 is monitored only during the week, while D5 is monitored the entire week even
though she feels she is capable of managing her own treatment, which is not allowed due to the program’s “rule” and to the fact that she does not want to cause any problems for the professionals providing care.

D5 was in her first TB treatment when was diagnosed as multidrug-resistant and D7 has been treated other three times. On one occasion, he was discharged for abandonment in addition to the fact that he was infected by a family member who was also an MDR-TB patient. Hence, these individuals provide different conditions of production that are not related to the care provided by the PHC service. It becomes apparent that the way MDR-TB cases are monitored is not related to the patient’s degree of autonomy, responsibility or vulnerability. Instead, monitoring is related to the way the PHC services are structured in the different contexts to care for these patients.

Therefore, after establishing how the MDR-TB patient will be monitored, according to the city’s criteria, the protocol cannot be changed, as the following excerpt shows:

*I wanted to see if the other physicians could come to my house and administer the shot and I’d take the medication at home. I go to the health unit every day and when it’s raining there’s no umbrella, their umbrella sucks, it breaks. And I can’t take the rain. Whoever has this health condition can’t take the rain, cannot stay without a mask. (D3).*

This excerpt shows difficulties related to access to health services expressed by the need for patients to commute to a health unit, configuring the local conditions of production that involve practices that lead to resistance as the individual makes a counterpoint or puts the professionals on equal terms as they would have to go to the patient’s home. “I wanted to see if the other physicians could come to my place” - these expressions reveal that the subject is silent, that there is no negotiation between patients and health workers in regard to treatment, suggesting that there are other situations that can interfere in the continuity of treatment such as ordinary situations: “there is no umbrella” or the more prescriptive “cannot stay without a mask”, which seems to show the difficulties of this patient in being acknowledged by the community as someone who is ill, who needs a mask.

Therefore, the report of D3 can be related to the report of D5, since the way DOT is provided is not appropriate for either of them. D5’s report identifies the organization of care at a local/city level as the one based on “rules”, on a protocol. This disciplinary order of the health services, which permeates the discourses of the patients, shows how complex and peculiar are the meaning patients assign to the supervised treatment. The discourses reveal that the mechanisms, methods, standards, and functions acquire a corpus of propositions that health professionals assume to the point that, regardless of the social position and role that institute or destitute patients, is disregarded by the professionals. Even though the protocols sometimes have flawed norms, they can be part of the conditions of production in DOT monitoring, providing solutions for situations of abandonment, failure and other conditions that lead patients resisting treatment, consequently facilitating new complications in drug resistance for drugs prescribed in the therapeutic process.

There is a need for DOT to go beyond the monitoring of medication and meet the needs of patients that emerge in their context of life. In this sense, the authors stress that, in addition to contributing to treatment adherence, DOT has the challenge to establish itself as a tool responsible for the reconstruction of meanings assigned to the health-disease continuum and to the process of becoming ill with TB, enabling adherence to concretize itself as a process rather than an imposition. The professionals and healthcare services, however, need to advance toward the concretization of this strategy, restricting treatment’s oppressive nature.

**CONCLUSIONS**

This study enabled analysis of the discourses produced by MDR-TB patients in regard to the monitoring and treatment of their disease. These reports are permeated by biological, psychological and social aspects. All these aspects are intrinsic to the illness process, to the discovery of the disease, to treatment and follow-up. We note that these meanings intertwine and constitute a network of meanings related to the process of becoming ill and living with resistance to anti-TB drugs.

The analyses highlight some actions to raise awareness of professionals in regard to the various problems that afflict patients. We note, however, some weaknesses related to the organization of the healthcare network in regard to the delivery of integral care to these individuals. Such obstacles may be characterized by a difficulty gaining cooperation among the services, (re)produced by unidirectional decision-making that hinders the coordination of different care levels.

In this sense, there are situations in which there is a lack of bonding between PHC and patients, in which only the patient is responsible in situations in which liability should be shared between patients and professionals. Additionally, the reports also refer to the inflexible attitudes of professionals, who are bound to protocols, with little space for negotiation and adjustment to the particularities of individual subjects and contexts. We also note there is a mismatch between the needs of patients and the way the services are organized, which are structured according to their own needs.

The limitations of this study involve the number of patients interviewed and the need to include health workers of both levels of care, in order to more broadly compose all the aspects involved in these conditions of production of MDR-TB treatment.

Finally, it is extremely important that other studies addressing this topic be conducted to enable a deeper understanding of this issue, including healthcare services, in order to identify and reflect on the actions that can be implemented to promote integral care delivery to MDR-TB patients.
Integral care provided to multidrug-resistant tuberculosis

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